The University of Chicago Law School Roundtable

Volume 3 | Issue 2 Article 8

1-9-1996

A Critique and Commentary on "The Road to Eugenics"

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Preparing my paper on Medicaid managed care and reproductive genetics gave me the opportunity to reflect on Dr. Bowman's very thoughtful and incisive essay on eugenics. Bowman explains how eugenics has been practiced from ancient times to the present. He further describes how some policies and programs, laws and regulations, have intentionally and inadvertently brought about eugenic practices and/or results.

Bowman stresses that minorities and other social undesirables are particularly at risk to eugenic practices. With the mapping of the human genome, problems which were once considered social in nature like alcoholism and criminal behavior will be linked to genetics. Thus, rather than being treated through traditional psycho-social remedies, these behaviors may be approached like other genetic disorders. This approach may allow us to dismiss our responsibility to address these problems as a society.

Bowman notes that laws and practices with eugenic implications are often designed for other purposes. Medicaid managed care was developed to capture soaring health care costs and to increase access to health care among the poor. Reproductive genetics creates a unique set of circumstances in the context of managed care which may also have unintended implications for low-income people and people of color. Medicaid managed care models ration the delivery of health care through gatekeepers and coordinators who decide what types of and how much health care will be available to an enrollee. These models raise serious questions about what kinds of health care problems deserve attention and care, how much care recipients should receive, and from whom they should recieve it. Decisions regarding these questions ultimately influence the health care choices people make, such as whether to keep or abort a "defective" fetus when the service may or may not be available or paid for. Thus, while the actions of gatekeepers and coordinators may not constitute intentional eugenics, the effect of these actions may be the same. As Bowman so clearly articulated in his presentation, "[s]cientific advances in genetics create a fertile ground for eugenics, because inequities in the delivery and costs of health care

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have led to plans for additional rationing of health care under the rubric of broadening the base of our market health care system to include those 37 million [uninsured] Americans who are merely bystanders to decent preventive health care and health."[1] Some of these 37 million Americans will be part of managed care models through waiver agreements drawn up by states to add new eligibles.

What impact will managed care have upon these and other low income families? Will this impact implicate eugenics? Will managed care discourage the birth of children with genetic disorders because of the perception that they represent a drain on the resources of health care plans and the profits of both the primary care physician and managed care practice? Will health care decisions reflect the rules governing managed care rather than the quality of care available?

As I consider Bowman's thoughts about eugenics in health care for individuals who are poor, black, or members of other minorities, it occurs to me that even though managed care is supposed to improve low-income families' access to care, a two-tiered health care system will persist in the United States because states will continue to regulate how, and in which ways, low-income families access health care. As I have previously written, Medicaid has imposed many restrictions on low-income women's access to prenatal diagnosis.[2] Under managed care, middle-income families will suddenly face similar restrictions as well, although probably to a lesser degree. Although both groups of women could be enrolled in the same HMO, different health care packages corresponding to disparate income levels will undoubtedly serve them separately.

Although I may imply above that a two-tiered system of health care is negative, there are some advantages to the kind of comprehensive care traditionally offered to low-income families through community health and federal programs. These advantages include outreach, follow-up, and familiarity with the needs of a low-income population. But what will be the incentive to reach out and provide health care services to a population when health care is capitated and prepaid in many instances under Medicaid managed care? There is concern as evidenced by the questions raised above about how well health care maintenance organizations and other managed care providers will be able to address the complex and varied needs of low-income and minority clients, particularly those who will use private doctors in the community. Examples of the varied services include the needs for transportation, case management, translation, interpretation, and one-stop shopping services for multi-problem families. Will these services be provided and to what extent?

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1. See generally James E. Bowman, *The Road to Eugenics*, 3 U Chi L Sch Roundtable 491 (1996).

2. See generally Laurie Nsiah-Jefferson, *Reproductive Genetic Services For Low-Income Women and Women of Color: Access and Sociocultural Issues*, in K.H. Rothenberg and E.J. Thompson, eds, *Women and Prenatal Testing: Facing the Challenges of Genetic Testing*, 234-59 (Ohio St 1994).

Why are many of the socially based health problems, such as mental health, substance abuse treatment, and other services for the disabled, carved out of many managed care models? Is it because of timed phase-ins or lack of expertise among the Medicaid providers, or could it be related to a need to restrict the access of these populations to such services? Anecdotal evidence from managed care providers has already shown that private practice offices have scheduled Medicaid clients on separate days from other clients. To some extent, this model prevails in managed care as well. In addition, anecdotal evidence from clients who have tried to disenroll indicates that they have had a very difficult time. This pattern corresponds to Bowman's statement that "[a]pparently, not only kings and queens, but also Fortune 500 executives are exempt from eugenic scrutiny. Consequently, eugenics is directed invariably to the poorer classes—to the defenseless."[3]

I am particularly pleased with Bowman's distinction between passive and active eugenics. He is correct to observe that neglecting to provide care to poor children and adults which results in preventable diseases is a form of passive eugenics. I would like to add to that observation that the selection of services to be offered under Medicaid managed care may be characterized in some cases as active eugenics against the poor. A 1994 CityMatCH study surveyed urban health department administrators and suggested that one of their major fears with respect to Medicaid managed care was that children would not receive immunizations or other preventative services not perceived as medical necessities.[4]

Bowman also discusses how eugenic precepts in the United States often lie firmly embedded in legislation and judicial decisions, even though lawmakers and judges may not possess eugenic intentions. Medicaid waivers to provide managed care services to poor families offer a further example supporting Bowman's thesis. Even if waivers exist to help reform the Medicaid system, they can be both helpful and harmful—helpful by eliminating inefficiencies in health care delivery under the Medicaid system and harmful through the service selection processes mentioned earlier. The distribution of waivers to states affects who receives preventive and genetic services, who is denied, and what levels of service are available to the poor. Waivers also raise questions about which states are more worthy of receipt or more capable of implementing these services effectively.

Bowman's discussion of law and practices that have intentional and inadvertent eugenic implications cites David Kairys' argument that the economic decisions that shape our society and affect our lives the most are not made democratically, or even by elected officials.[5] Law and the state are not "neutral, value-free arbiters, independent of and unaffected by social and economic

3. Bowman, 3 U Chi L Sch Roundtable at 493 (cited in note 1).

4. See generally CityMatCH at the University of Nebraska Medical Center, Dept of Pediatrics, *Changing the Rules: Medicaid Managed Care and MCH in U.S. Cities* (1994).

5. Bowman, 3 U Chi L Sch Roundtable at 501-02 (cited in note 1).

relations, political forces, and cultural phenomena. Traditional jurisprudence largely ignores social and historical reality, and masks the existence of social conflict and oppression with ideological myths about objectivity and neutrality."[6] This particular idea relates to managed care because policy makers, as dominant sources of power, make decisions about the types of service which will be available, and how they will be delivered to poor people.

Similarly, many managed care providers may know much more about the needs of their moderate to middle-income clients as opposed to those of their low-income clients. Under Medicaid managed care, it is conceivable that after years of developing and conceiving programs for women and children that were sensitive to their needs, this low-income population may now face integration into models that are either insensitive or unable to address the myriad health care services required by the diversity of women's lives. The 1994 CityMatCH study noted that local health department administrators believed that the complex health care needs of underserved populations simply will not be addressed adequately by the private sector providers who agree to participate in the managed care system.[7] Administrators fear that families with special needs will see these needs unfulfilled under Medicaid managed care and that additional families who may need care will neither be sought out nor served. Urban health departments predicted that people at greatest risk for health problems will fall through the cracks in the absence of aggressive case management and support services such as transportation, translators, and child care. Just as Bowman discusses how a lack of understanding among health care planners led to the shortcomings of sickle-cell screening and testing programs in the 1970s and 80s, managed care is at risk of a similar lack of knowledge in developing its programs. Health care lessons learned over many years by public and community-based programs will have to be learned again by those providing care in the managed care environment unless collaboration between providers is encouraged and practiced.

Bowman also addresses Margery Shaw's discussion of recovery for fetal injuries to children born with disabilities.[8] Shaw indicated that in most situations the defendant would be the mother, because of her direct connection to the fetus. Bowman notes that negligent exposure to noxious chemicals and drugs, refusal to accept genetic counseling and prenatal diagnosis and refusal of prenatal therapy could be grounds for a law suit. I would add that the state should also be liable by refusing services to low-income women and children. The argument can be extended to include managed care plans or the states that mandate rules for these plans if negative client outcomes can be proven to have been caused in part by denial, unavailability, or nonauthorization of

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6. David Kairys, ed, *The Politics of Law: A Progressive Critique* 4 (Pantheon 1982).

7. See generally CityMatCH at the University of Nebraska Medical Center, Dept of Pediatrics, *Changing the Rules: Medicaid Managed Care and MCH in U.S. Cities* (cited in note 4).

8. Bowman, 3 U Chi L Sch Roundtable at 511-12 (citing Margery W. Shaw, *Conditional Perspective Rights of Fetus*, 5 J Leg Med 63 (1984)).

services. A case with these characteristics was brought to trial in Massachusetts.[9]

Bowman argues that the rights of a fetus are often pitted against maternal duties and rights and notes that pregnant women who drink alcohol or who are cited for drug abuse have been censured and even incarcerated.[10] Fetal abuse is equated with child abuse. Over the last five years, I have been working on a research project involving drug addicted pregnant and postpartum women and their children. The issue of state intervention in the lives of these women has proven to be extremely controversial. Nevertheless, after reviewing the histories of these women, it has become apparent that many lack sufficient control of their lives to counteract the assaults which influenced their initial and continued use of substances. It has also become apparent, however, that the intrusions into their lives by some child protection agencies do not always facilitate recovery. In other words, we cannot continue to blame victims entirely for all the ills that they and their children suffer.

The course of this research has further revealed to me that managed care models have the potential to interfere with creative service delivery mechanisms for pregnant and postpartum addicted mothers due to carve-outs in managed care services of substance abuse services for addicted mothers. Creative programs have been developed to combine prenatal care and drug treatment. Services under Medicaid managed care, however, may separate these services so that the benefits of combined treatment are either lost or made to require the development of new mechanisms if they are to be maintained.

Having studied women who voluntarily joined managed care networks and were told that they could no longer access the prenatal portion of their medical services through their combined programs of prenatal care and drug treatment, I appreciate the frustrations of having to disenroll from managed care and reapply for Medicaid. This time consuming and laborious process potentially affects not only a woman's physical and mental health, but also the health of her child. Women who remained enrolled in the managed care environment may have received only disjointed health care services—less than optimal care.

Bowman also addresses the issue of mental health services and discusses prevention of such disorders through genetics. I believe that even if we could prevent mental illness, we could prevent only certain types. In my opinion, many psychological ills are caused largely by inappropriate demands on otherwise normal people who are stressed by poverty, discrimination, and hopelessness. In addition, it should be noted that depression and other illnesses are not always detrimental to our personal and societal growth. Working and living with such individuals in society may enrich and improve our lives by helping us to recognize our own strengths and weaknesses.

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9. *Chase v Independent Practice Association*, 583 NE2d 251 (Mass App 1991).
10. Bowman, 3 U Chi L Sch Roundtable at 512 (cited in note 1).

Finally, Bowman's discussion of Ingle's thesis on the rights of reproduction and the poor, relates to the Medicaid managed care issues of access to family planning services, types of contraception, and abortion availability.[11] In some states, these types of services are carved out from the package of available services.[12] I find the impulse behind this approach to be truly disturbing. Perhaps some lower income parents should not have children. But some middle-class and privileged parents should not have children either. They may not be materially impoverished, but they may be emotionally distraught, devoid of love and care, and otherwise inappropriate parents. I do not believe that only certain types of people can be parents; while it is important for parents to be able to support their children, many very poor and humble families have raised absolutely wonderful citizens.

I hope for a growing dialogue between communities, managed care providers and state legislators about managed care policies and regulations. This may stave off some potential eugenic outcomes which might otherwise result from managed care practices.

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11. Id at 514-15.

12. David J. Ingle, *Who Should Have Children?: An Environmental and Genetic Approach* 81 (Bobbs-Merrill 1973).